

Empowering Hoosiers: Advancing Less Restrictive Alternatives to Guardianship in Indiana

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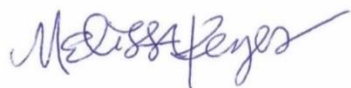
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FOREWARD

Indiana Disability Rights (IDR), in partnership with the Indiana Institute on Disability and Community (IIDC), along with key stakeholders, has prepared the following plan with a focus on advancing the use of less restrictive alternatives (LRA) to guardianship in the state of Indiana. Guardianship most often impacts people with intellectual and developmental disabilities, elder adults, and people with mental health conditions. Previous research in to the judicial system in Indiana reveals that guardianship has been a first option, rather than a last. This over-utilization occurs in many cases without supporting evidence, without testimony from the affected person, and without reassessment, leaving people to languish under guardianship for many years, without a plan or supports to regain their legal rights. In 2019, legislation was passed in the state of Indiana, offering an opportunity to disrupt this cycle. The law, *SEA380*, requires the prioritization of Less Restrictive Alternatives, and in cases where guardianship is deemed appropriate, the reasons why LRAs are not employed.

Since 2019, stakeholders have met to develop a plan to move Indiana forward in to a future where individuals retain their rights, and where guardianship is employed after alternatives have been exhausted, rather than as a first step. This plan was developed in partnership with stakeholders, including individuals and representatives from organizations invested in partnering to advance Less Restrictive Alternatives to guardianship for all Hoosiers. We heard directly from people with intellectual and developmental disabilities, people with disabilities, elder adults, self-advocates, advocates, family advocates, and providers about issues, challenges, and unmet needs related to accessing Less Restrictive Alternatives in their personal lives, and in their communities.

Working together, we are committed to continuing a coordinated effort involving stakeholders to support self-determination, choice-making, and making access to SDM and LRAs accessible to all Hoosiers impacted by the guardianship system, as outlined in this plan, *Empowering Hoosiers: Advancing Less Restrictive Alternatives to Guardianship in Indiana*.



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EXECUTIVE SUMMARY

Goal 1: Empower populations impacted by guardianship, and support self-determination and self-direction with accessible, comprehensive, and factual information to make informed decisions.

- A. Ensure the availability and accessibility of information to all stakeholders about options for supported decision-making and other less restrictive alternatives
- B. Provide enhanced outreach and education to individuals who are at risk for guardianship to assist in empowering individuals to engage in self-determination and supported decision-making.
- C. Ensure informational efforts are evaluated and sustained for long-term impact.

Goal 2: Build statewide capacity for increased use of less restrictive alternatives to guardianship, improving the collective ability of systems to facilitate the practice of LRAs.

- A. Promote and support successful integration of principles of LRAs in to systems serving people with disabilities, older adults, and people with mental health conditions.
- B. Create culture shift toward promulgating and proliferating self-determination through the use of LRAs by leveraging relationships and providing education to partners, guardianship referral sources, affected professions, and the community.
- C. Provide support and resources to affected professions to ensure they are aware of and assisted in adapting to SEA 380's regulations.
- D. Expand opportunities for community involvement to increase the availability and use of LRAs, promoting peer-to-peer support and training, and family supports.

Goal 3: Implement innovative policies and best practices to support, prioritize and sustain the use of LRAs.

- A. Evaluate the implementation of Senate Enrolled Act 380 and guidelines to identify best practices and promising ways to move use of LRAs forward.
- B. Develop, implement, and evaluate innovative, best practices that support the advancement of LRAs.
- C. Promote awareness of the benefits of LRAs, promote awareness of abuse against populations at risk for guardianship, and effective prevention strategies.
- D. Evaluate the outcomes of LRAs and guardianship practices for people with disabilities, older adults, and people with mental health conditions.

SECTION I. PURPOSE AND VISION

State Plan Purpose

This purpose of this document is to propose a plan for the state of Indiana including action steps to increase the use of less restrictive alternatives (LRAs), including supported decision-making (SDM) as an alternative to the use of guardianship. This plan focuses on making changes to the systems that interact with those groups most impacted by the use of guardianship in Indiana, people with intellectual and developmental disabilities, people with other disabilities, and people who are aging. This plan proposes systemic changes, with a belief that the power and resources for change exist within the communities of people most impacted by guardianship: people with disabilities and elders. The development of this plan is funded by the Administration for Community Living.

Vision and Values

Vision

All people have the right to live free of abuse, neglect, exploitation, discrimination, and marginalization and have a right to exercise self-determination and self-direction to the greatest extent. All people should be valued, respected have their many identities celebrated, including culture, race, ethnicity, sex, gender, affectional or sexual orientation, disability, age, and any other expressions of their authentic self.

Values

- Self-determination, choice, and respect
- Self-direction in services and supports
- Less restrictive/least restrictive options to support someone
- Recognition of interdependence, instead of requiring independence
- Respecting the dignity of risk
- Full community membership
- People having the decision-making support they need
- Changing the system by addressing systemic failures leading to abuse, neglect, exploitation, discrimination, and marginalization
- Presumption of capacity
- Peer-to-peer facilitation, leadership, and collaboration (“we are our own best experts”)
- Change the culture of guardianship as the default option
- Challenging assumptions about the strengths and needs of people with disabilities, older adults, and those with mental health issues
- Appreciation for multiple intersecting identities
- Educating people about their rights
- Equitable access

SECTION II. BACKGROUND AND CONTEXT

Overview

This project aims to develop an action plan to address the systemic barriers to accessing less restrictive alternatives to guardianship, and to promote the use of less restrictive alternatives to guardianship in the state of Indiana. Individuals with intellectual and developmental disabilities, other disabilities, elder adults, and people with mental health conditions face systemic barriers when trying to live their lives with self-determination and autonomy. This plan will focus on systemic issues in an effort to support individuals' empowerment. As per the funding of this project, and in line with data on guardianship practices, this plan both focuses on individuals with intellectual and developmental disabilities and elder individuals, as well as recognizes that this issue impacts communities beyond those, including all people with disabilities. This plan engages the broader disability community to work toward implementing LRAs in Indiana. The goal of this plan is to reduce systemic barriers to accessing LRAs and to empower individuals and families with access to less restrictive alternatives to guardianship. There are two central issues with access to LRAs this plan addresses: 1) a systemic lack of understanding of LRAs, which results in an over-reliance on guardianship; and 2) a lack of access to legal services and practices to help preserve or restore a person's self-determination and self-direction.

Indiana context

Approximately 16% of Indiana's population is 65 years or older and 10% are considered persons with disabilities under the age of 65 (U.S. Census Bureau, 2019). Indiana's guardianship process varies slightly by county, and while persons are able to have legal representation, there is no state-supported counsel resulting in the majority of guardianships being uncontested and persons being unrepresented by legal counsel to advocate for their rights. Past reviews of state data indicate that in many cases, no evidence of incapacity was ever filed with court beyond the allegations in the guardianship petition. Without legal help, such as a guardian ad litem, a person may be ill-equipped to protect their rights, and the court is left without proper information to make an appropriate determination. In 2019, Senate Enrolled Act 380 was passed and signed in to law. The legislation does two things: 1) it adds a requirement that a petitioner for guardianship include information about whether LRAs, including SDM, were considered or implemented prior to seeking guardianship; and 2) it provides legal recognitions of SDM agreements as a LRA and codifies requirements for those agreements. This legislation lays important groundwork for making meaningful and sustained change around guardianship issues in the state of Indiana. This plan addresses the coordinated efforts needed across systems to ensure the implementation of SDM and LRAs in Indiana.

Development of State Plan

The project was led by the Principal Investigator (PI) Melissa Keyes, Executive Director of Indiana Disability Rights in close partnership with Derek Nord, Executive Director of the Indiana Institute on Disability and Community (IIDC) and Kristin Hamre, affiliate faculty at

IIDC. The state plan was developed with input from key stakeholders, who reviewed and provided input to draft the plan. Project leads consulted with these organizational partners to identify shared priorities and opportunities for collaboration in achieving these objectives. The Steering Committee met every other month to conduct planning, and, in partnership with the Steering Committee, feedback sessions convening key stakeholders were held on opposite months. Steering committee and stakeholder meetings consisted of priority-setting, goal development, and input on objectives. Additionally, as the plan began to take form, it was presented at stakeholder meetings to garner additional feedback.

To prioritize the voices of individuals with disabilities, elder adults, and people from historically marginalized communities, a number of peer-led sessions were conducted to garner input and feedback on the plan. Peer leaders underwent training to present the state plan goals and to receive feedback from peers, taking notes, and sharing those with the Steering Committee (some of whom led peer sessions as members of the community). Note-takers were offered. The peer-led sessions gathered valuable feedback and input. This information was utilized directly in the plan, and prioritized the voices of those most impacted by the systemic issues influencing the use of guardianship and the implementation of LRAs. Over several sessions, nearly 100 people representing various backgrounds, including people with intellectual and developmental disabilities, people with other disabilities, and elders attended a peer-led session and offered their input to the plan.

Engagement and outreach with communities of color

In order to reach all Hoosiers, it is important to understand the unique context, including strengths, resources, as well as outreach and education needs of communities of color across Indiana around issues of guardianship and LRAs. It is important that outreach is inclusive, supportive, and celebratory of communities of color in an intentional and systemic manner. This approach is strengths-based, and emphasizes the many resources that exist in communities of color. In addition to the peer-led sessions, which included intentional outreach to individuals from historically excluded and marginalized communities, outreach began with communities of color. This will be an ongoing process.

The COVID-19 pandemic has highlighted existing health and access disparities. For example, according to the Centers for Disease Control and Prevention (CDC), Black people have been hospitalized three times more than white people for COVID-19, and systemic issues including racism, access to health care, education, and income equality are identified among the contributing factors. To build upon the work done in the peer-to-peer sessions to reach diverse voices, community-level outreach began. Relationships were made with members from the Burmese and the Spanish-speaking communities. Details from these sessions can be found in Appendix C. This plan prioritizes including outreach strategies to include communities of color in future efforts to expand the awareness and use of SDM and LRAs. Based on conversations with representatives of the two most prevalent cultural linguistic groups in Indiana, Burmese and Spanish-speaking, there were several recommendations which assisted in developing this plan and prioritizing the experience of communities of color, including on education, outreach

strategies, and knowledge dissemination. It is vital that this engagement continues with intention to empower and center communities of color as we work to increase the use of LRAs in Indiana.

Upon completing a final draft of the state plan, it was presented to the stakeholder group and additional feedback was incorporated. The draft State Plan was posted on the IDR and IIDC websites and open for public comment. A period of public comment lasted from July 1, 2021 to July 31, 2021. Public input was taken in to consideration in development of the final version of the plan.

SECTION III. GOALS AND OBJECTIVES

Guiding Principles

All people have capacity, skills, knowledge, and potential. It is important to center the work of empowering individuals who are at risk for guardianship, and to support the self-determination, self-direction, and decision-making capacity of impacted individuals and populations. For this to occur, people must be aware of their options and have the skills to advocate. Families must have this information early in their family member's lives. Information empowers people to make decisions about their lives, and supports must be provided in a way that promotes self-determination and self-direction.

In addition to empowering individuals and family members, it is critical to remove systemic barriers, so that those attempting to exercise their rights are not deterred. Individuals may have intersecting identities which may result in being further marginalized by systems of oppression. Without systemic changes, individuals, even when equipped with knowledge and empowered to make their own decisions, will face barriers to accessing LRAs. It is vital that efforts aimed at increasing the use of LRAs focus on systemic change, and on change which seeks to undo oppressive systems across race, class, gender, disability, age, and sexual orientation. Available information suggests that LRAs are not readily accessible to Indiana residents. A review of court documents suggest that most cases which are reviewed for guardianship result in plenary guardianship, regardless of evidence indicating appropriateness of this option. It is important to understand what systemic and other barriers exist in accessing LRAs across communities. While accessing LRAs is a systemic issue requiring systemic changes, it is vital to understand that the power and solutions lie with the people and communities who are most impacted by guardianship.

Timeline and partnerships for goals and objectives

Goals and objectives are intended to be implemented during the next year, with some goals being worked on during the grant cycle. Strategic partners are identified in the goal tables, with specific potential partners identified in Appendix A. In the tables below, the lead entities for moving a goal's action steps are identified; those entities taking the lead are marked with a check in the box. It is understood that while all entities may partner and have a role in moving an action step forward, there are those entities which will take more of a direct role in doing so. Self-advocacy and advocacy groups are checked in all boxes to acknowledge their unique roles

as leaders in the community who must be centered in each step. In addition to self-advocacy and advocacy groups, Indiana's Governor's Council for People with Disabilities (GCPD), government, Indiana Disability Rights (IDR), Indiana University's Indiana Institute on Disability and Community (IIDC), and provider groups are represented in the tables as they are well-positioned entities to begin moving tasks forward in service of systematically advancing LRAs in Indiana. Other organizations may also play a role in advancing LRAs.

GOAL 1. Empower populations impacted by guardianship, and support self-determination and self-direction with accessible, comprehensive, and factual information to make informed decisions.

Objective 1A: Ensure the availability and accessibility of information to all stakeholders about options for supported decision-making and other less restrictive alternatives

Goal 1, Objectives A – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
1.A1	Identify collaborators at risk or impacted by guardianship across the lifespan to serve as leaders in developing the communication plan, content development, and delivery.	✓	✓					✓
1.A2	Identify and support continuation of available resources aimed at educating people across the lifespan about LRAs.	✓	✓	✓	✓	✓	✓	✓
1.A3	Ensure direct support professionals, providers, agencies, and systems have access to information about LRAs and supported decision-making.	✓	✓		✓	✓	✓	✓
1.A4	Develop and publish new material with partners, including web-based content and resources (IIDC, IN Disability Rights, etc).	✓	✓			✓	✓	

Objective 1B: Provide enhanced outreach and education to individuals who are at risk for guardianship to assist in empowering individuals to engage in self-determination, self-direction, and supported decision-making.

Goal 1, Objective B – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
1.B1	Collaborate with state agencies to promote and integrate language on LRAs.	✓	✓	✓	✓	✓	✓	✓
1.B2	Engage individuals and family members in various settings across the lifespan (e.g. Transition fairs).	✓	✓	✓	✓	✓	✓	✓
1.B3	Collect and disseminate personal stories with using LRAs to provide examples, and address family and individual questions.	✓	✓	✓		✓	✓	
1.B4	Develop a peer-to-peer program to provide leadership, support and information.	✓	✓	✓	✓			
1.B5	Create a media campaign utilizing social media, direct mail, public entities (eg, the library), radio, websites (e.g. YouTube) to share information and reach a wide range of people.	✓	✓					
1.B6	Engage with partner organizations to introduce field-specific communication (e.g., the State Bar Association).	✓	✓			✓	✓	

Objective 1C. Ensure informational efforts are evaluated and sustained for long-term impact.

Goal 1, Objective C – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
1.C1	Convene key stakeholders to evaluate the efficacy of outreach and educational materials, and make necessary edits for accessibility and usefulness.	✓	✓			✓	✓	
1.C2	Provide ongoing training, technical assistance, and resources on LRAs and utilization of LRAs to impacted groups.	✓	✓			✓	✓	
1.C3	Introduce policy to require systemic changes to prioritize dissemination of information on, training related to, and use of, LRAs.	✓	✓	✓		✓		
1.C4	Develop a permanent website linked through specific entities to provide ongoing support and information.	✓	✓			✓		

GOAL 2. Build statewide capacity for increased use of less restrictive alternatives to guardianship, improving the collective ability of systems to facilitate the practice of LRAs.

Objective 2A: Promote and support successful integration of principles of LRAs in to systems serving people with disabilities, older adults, and people with mental health conditions.

Goal 2, Objective A – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
2.A1	Incorporate principles of LRAs into things like waiver redesign, LifeCourse, transition planning, case management processes, and self-directed waiver program.	✓	✓		✓			
2.A2	Build processes to include these principles across professions (e.g. re-development of physician statement to include LRAs and strength-based language and framework).	✓	✓			✓		
2.A3	Identify ways to disrupt the pathway in to guardianship, and minimize costs for people to utilize LRAs.	✓	✓			✓		✓
2.A4	Encourage systems advocacy efforts by disability and aging-led organizations (grassroots, legislative, policy). Create messaging templates and toolkits for public comments.	✓	✓					
2.A5	Analyze current rules and regulations to address barriers to using LRAs and exercising self-determination.	✓	✓			✓		✓
2.A6	Proactively monitor developing laws, regulations, etc. to incorporate principles of self-determination whenever possible.	✓	✓	✓		✓		

Objective 2B: Create culture shift toward promoting and increasing self-determination through the use of LRAs by leveraging relationships and providing education to partners, guardianship referral sources, affected professions, and the community.

Goal 2, Objective B – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
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2.B1	Leverage buy-in from partners to expand the awareness of and capacity to support the use of LRAs. Efforts should be inclusive of multi-cultural, multiple marginalization, diverse communities. Potential partners included in Appendix A.	✓	✓	✓	✓	✓	✓	✓
2.B2	Shift the conversation of guardianship referral sources to include LRAs. Entities who can speak with knowledge about the subject and make strong referrals should be targeted. An initial list of potential referral sources is included in Appendix B.	✓	✓		✓			✓
2.B3	Develop tailored education and training for these referral sources.	✓	✓			✓	✓	
2.B4	Provide technical assistance for referral sources as they acclimate to the new spectrum of options to refer.	✓	✓		✓	✓	✓	✓
2.B5	Advance policy to bolster use of LRAs. Such as: mandatory guardian ad litem as a tool to move people towards LRAs, to being able to state their own wishes (Adult Guardianship Act)	✓	✓	✓		✓		

Objective 2C: Provide support and resources to affected professions to ensure they are aware of and assisted in adapting to SEA 380's regulations.

Goal 2, Objective C – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
2.C1	Find and train attorneys who can assist in draft LRA documents.	✓	✓			✓		
2.C2	Provide tools and resources, including how to draft LRAs.	✓	✓			✓		
2.C3	Ensure those in legal, education (K-12), medicine, and social work professions know what LRAs are and the processes around them.	✓	✓			✓	✓	

Objective 2D: Expand opportunities for community involvement to increase the availability and use of LRAs, promoting peer-to-peer support and training, and family supports.

Goal 2, Objective D – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
2.D1	Build self-advocacy groups to support people across the lifespan.	✓	✓					
2.D2	Train individuals to deliver messaging.	✓	✓					✓
2.D3	Identify self-advocates to co-train/lead trainings on self-determination, as indicated in Goal 1, part B. Focus on peer-to-peer and disability/older adult led-trainings (co-trainings).	✓	✓					
2.D4	Secure funding for speakers through avenues such as the Arc/SAI's speaker's bureau.	✓	✓					
2.D5	Seek buy-in from multiple communities about LRAs to honor their use. "Capitalize" on current events, such as implications of the Coronavirus, to highlight the importance/use of LRAs.	✓	✓					
2.D6	Educate people with disabilities, older adults, and those with mental health conditions to know about LRAs and their rights. Create and disseminate resources and tools, as described in goal 1 to increase knowledge and understanding.	✓	✓	✓	✓	✓	✓	✓
2.D7	Develop attorney referral list, similar to pro bono referral lists, for the community access professional support.	✓	✓		✓	✓		
2D.8	Expand opportunities for community involvement to increase the availability and use of LRAs, promoting peer-to-peer support and training, and family supports.	✓	✓					✓

GOAL 3. Implement innovative policies and best practices to support, prioritize and sustain the use of LRAs.

Objective 3A. Identify, develop, and implement best practices and promising ways to move use of LRAs forward.

Goal 3, Objective A – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
3.A1	Implement necessary operational changes to ensure compliance with Senate Enrolled Act 380.	✓	✓			✓		

3.A2	Conduct case studies to identify and determine individual, professional, organizational, and systemic practices that increase self-determination.	✓	✓			✓		
3.A3	Implement training aimed at developing best practices within systems (e.g. educational, judicial, medical, case management).	✓	✓		✓			✓
3.A4	Develop and test practices that increase opportunities for people under guardianship to learn about their options, including in manners that optimize peer supports and self-advocacy approaches.	✓	✓					✓
3.A5	Develop and test educational and decisional support interventions in traditional face-to-face and technology-based mediums.	✓	✓					✓
3.A6	Identify sustainability mechanism, such as waiver funds, Money Follows the Person, and other disability funding for decisional supports.	✓	✓		✓			
3A.7	Develop and test court models for guardianship to more effectively advance LRAs and allow individuals to participate in and appear on their own behalf (e.g., remote court options, CASA model).	✓	✓		✓			
3A.8	Promote awareness of the benefits of LRAs, promote awareness of abuse against populations at risk for guardianship, and effective prevention strategies.	✓	✓	✓	✓	✓	✓	✓

Objective 3B. Evaluate systems, policies, and practices related to the use of LRAs.

Goal 3, Objective B – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
3B.1	Create a monitoring system to collect data and provide oversight of the guardianship process and practices.	✓	✓		✓			
3B.2	Conduct research to explore facilitators and barriers to LRAs that relate to systems, professionals and individual characteristics.	✓	✓				✓	

3B.3	Explore alignment opportunities with state data collection programs to allow for inclusion of LRA-related data. For example, National Core Indicators, and other state agency data activities.	✓	✓		✓	✓	✓	
3B.4	Develop a plan to conduct outcome evaluation and research related to LRA and guardianship practices across living arrangements, that include: purpose, research and evaluation questions, methods and data sources, and timeline.	✓	✓			✓	✓	
3B.5	Seek funding to conduct evaluation and research via grant, foundation, and in-kind support.	✓	✓				✓	✓

Objective 3C. Promote awareness of the benefits of LRAs, promote awareness of abuse against populations at risk for guardianship, and effective prevention strategies.

Goal 3, Objective C – Action Steps

Objective	Action Step	Self-Advocacy	Advocacy	GCPD	Government	IDR	IIDC	Provider
3C.1	Develop and disseminate information/fact sheets about different decisional supports (SDM, POA,) and rights/risk to individuals and families.	✓	✓					✓
3C.2	Conduct training and education to legal professionals and judges.	✓	✓		✓	✓		
3C.3	Develop and implement decision-making curriculum for young adults and families, before an individual turns 18.	✓	✓				✓	
3C.4	Advance policy requiring certification for guardians in the state of Indiana.	✓	✓			✓		
3C.5	Develop a formal communication plan to increase awareness that addresses target audiences (e.g., individuals, family members, professional type, etc.); strategy to communicate across diverse groups, including those across different cultural and linguistic, age, geographic dimensions; mediums to reach; timelines and responsibilities.	✓	✓					✓

SECTION IV. SUSTAINABILITY

We believe this plan sets a course to implementing the steps needed to increase the use of LRAs in Indiana. There has been an overuse of guardianship in the state of Indiana. This plan outlines goals and objectives, and identifies partners to work strategically to change the systems which result in a reliance on guardianship in Indiana. By collaborating with partners in legal, advocacy, provider, research, and the broader community, this plan lays the foundation for a future in which all Hoosiers will be able to exercise self-determination and access less restrictive alternatives to guardianship.

SECTION V. APPENDICES

Appendix A. Partners to expand awareness of and capacity to support LRAs.

- i. Indiana Disability Rights
- ii. Indiana Institute on Disability and Community
- iii. Arc of Indiana
- iv. Centers for Independent Living
- v. Self-Advocates of Indiana
- vi. Self-advocate organizations
- vii. AKTION Clubs
- viii. Clubhouses for serious mental illness
- ix. ASAN
- x. Hoosier Alliance on Neurodiversity
- xi. Advocates in Action
- xii. National Association of the Deaf
- xiii. Youth Move Indiana/South East (youth < 30 w/ mental health needs)
- xiv. Evansville self-advocates (Gary May)
- xv. Villages of Merici Resident Council
- xvi. National Federation of the Blind
- xvii. Indiana Association of the Deaf
- xviii. DAV
- xix. AARP
- xx. Residents' councils at facilities
- xxi. Senior centers
- xxii. AAAs
- xxiii. Mayor Advisory Councils
- xxiv. Union Retiree Councils/Organizations
- xxv. State agencies (FSSA/DDRS/DFR)
- xxvi. Trade associations
- xxvii. VOCART

Appendix B. Guardianship referral sources, initial list of potential referral sources.

- a. AAA
- b. Options Counselors
- c. Case Managers
- d. Educators
- e. Centers for Independent Living
- f. Self-Advocates of Indiana
- g. Family Voices
- h. Providers

- i. Medical Community
- j. Hospital Social Workers
- k. Social Security
- l. Peer-to-peer
- m. Family-to-family
- n. Police/First Responders
- o. APS
- p. DCS, especially for transition aged children
- q. Nursing homes
- r. Group homes
- s. Jails/prisons
- t. Prosecutors/Public Defenders
- u. Etc.

Appendix C. Burmese and Spanish Speaking Session Notes

In addition to the one-year extension creating an opportunity to conduct intentional peer-to-peer discussion groups, the additional time allowed for connection with representatives from under-represented cultural-linguistic groups. It is widely understood that disability and aging do not discriminate; these conditions and life experiences can affect anyone. Exposure to, and understanding of guardianship and LRAs, may be impacted by language and culture. In order to reach all Hoosiers, it is important to understand the unique outreach and education needs of the diverse populations across Indiana.

According to the IU Center for the Study of Global Change's Indiana and World Languages Report, 8.4% of people in Indiana's population speak a language other than English at home. Furthermore, Faitha Guessabi, a professor of Languages and Translation at the Université de Béchar in Algeria, explained in *Language Magazine* that, "the way in which we think about the world is directly influenced by the language we use to talk about it." This means that 8.4% of Indiana's population is likely to have different perceptions of how to support those with disabilities. If, "language and culture are homologous mental realities," as Guessabi asserts, it is imperative for the SDM State Plan to include intentional outreach strategies which are appropriate to various groups' unique needs.

To learn more about what those needs are, representatives from the Burmese and Spanish communities were interviewed. This section will detail the information learned from those conversations and provide recommendations on how to conduct effective education and outreach to Indiana's two largest cultural linguistic minority communities.

Burmese Community

Conversations with representatives of the Burmese community resulted in an understanding of the community's perceptions of support, recommended outreach topics, potential outreach strategies, and language translation recommendations.

Burmese culture appears to already be informally practicing the principles of supported decision-making. According to Interviewee 1, Burmese families tend to be supportive of individuals who

need assistance in their day-to-day life (personal communication, January 26, 2021). They explained that this is a natural part of family culture in Myanmar. Relatedly, they noted that in Myanmar, there is not a clear legal path to guardianship. Because of the supportive family culture, there may not be a need for legal guardianship.

Based on this information, Interviewee 1 recommended that initial outreach focuses on providing education regarding the differences in the American court systems, benefits of advance planning, and reasons to formalize the support systems many families are already using in daily living. Interviewee 2 agrees with Interviewee 1's recommendation, noting that before alternatives can be explored, many individuals will first need to receive education about what guardianship is (personal communication, January 7, 2021 and February 2, 2021). Similarly, Interviewee 2 advised that definitions of capacity and what it means to be incapacitated will need to be explained. Another topic Interviewee 2 suggested for initial outreach is education regarding situations in which SDM and LRAs would be used. Perhaps, they noted, even including what types of disabilities generally would benefit from these of support would be beneficial.

Another topic that may not be well-known yet to the Burmese community is the importance of advance planning. Outreach was suggested by Interviewee 2 to explain the benefit of learning about guardianship, SDM, and LRAs before it is too late. For example, an adult with a disability whose parent typically assist with day-to-day activities may suddenly find themselves unable to receive support from their parent if they are taken to the emergency room (ER). Although the parent is able to informally provide daily supports, many hospitals require formal permissions, such as a Power of Attorney, Healthcare Representative Agreement, or a Supported Decision-Making Agreement to allow an adult's parent to be present in the ER. Without formal supports arranged in advance, a person with a disability may not have access to their support system when they need it most.

When conducting initial outreach and building new relationships in the Burmese community, both Interviewee 1 and Interviewee 2 noted that it is important for written outreach materials to include a statement about communication access. They both explained that being upfront about how subject matter experts will communicate – via an interpreter, bilingual staff, etc. – is a valuable step in building trust and conducting inclusive outreach. Knowing that they can have a conversation in their preferred language will increase the willingness of individuals to seek assistance.

Interviewee 1 also explained that it is best to keep written outreach materials brief. Interviewee 2 agreed, specifying that infographics tend to be most effective. Interviewee 2 wisely noted that images cross language barriers. These types of materials can be used to generate interest which results in personal contacts. Both Interviewee 1 and Interviewee 2 agree that personal contact is more effective than written materials. Regarding live outreach, in-person or virtually, Interviewee 1 explained that groups facilitated by a trusted entity like the Burmese American Community Institute (BACI) with the subject matter experts joining as guests are likely to be most effective.

In addition to the BACI, Interviewee 2 suggested including the following organizations in the SDM State Plan's outreach to the Burmese and larger immigrant communities:

- Chin Center
- Immigrant Welcome Center
- Ft. Wayne Burmese Center
- Indiana Legal Services – Immigrant Rights Center
- Neighborhood Christian Legal Clinic

Regarding translation, Interviewee 2 recommended implementing a two-phase process to establish quality control. When they request translations as part of her role with the courts, they first send the materials to a translation agency. After materials are returned, they have the translations reviewed by a qualified, independent translator. Any changes the independent translator identifies are sent back to the agency for editing. The final product ensures all information is accurately communicated. Interviewee 2 recommended this group follow a similar system.

Interviewee 1 noted that the top languages for central Indiana are Burmese and Hakha Chin. Interviewee 2 expanded on this, explaining that Burmese is the official language in Myanmar. Burmese is only learned, however, by those who have received formal education. Many immigrants, therefore, do not know Burmese or may have negative cultural associations with it as the language used by their former oppressors. Regarding the variety of ethnic languages in Burmese culture, Interviewee 2 explained that many are used in Indiana regionally. The top two requests the courts receive, however, are for Hakha Chin and Karen S'gaw. A list of ethnic languages can be found by visiting the Court's "I Speak Guide," available at <https://www.in.gov/courts/admin/files/intrprt-i-speak-guide.pdf>.

While the Burmese community is already informally practicing the concepts of supported decision-making, there is still a unique need to provide education on the benefits of formalized supports. Explanations of the basic concepts, when formal supports could be used and importance of advance planning, are all recommended topics to include in future outreach. Additionally, outreach materials should include a note about how to communicate and be as brief and image driven as possible. Finally, outreach is likely to be most effective when done in cooperation with a trusted community partner. With those recommendations in mind, the SDM State Plan can ensure effective and inclusive outreach for the Burmese community of Indiana.

Spanish-Speaking Community

Conversation with a representative of the Spanish-speaking community resulted in an understanding of the Spanish-speaking community's perception of supports, topics for outreach, and outreach strategies.

Within the Spanish-speaking community, Interviewee 3 explained that culturally, when a child or individual has a disability, the family tends to make decisions for them (personal communication, January 22, 2021). Options to empower the person with a disability, like SDM and LRAs, will be new and exciting for the community. Therefore, just as with the Burmese community, initial outreach will need to focus on education regarding what guardianship, SDM, and LRAs are and when/why they may be needed.

Much like the Burmese community, Interviewee 3 explained that it is most effective to have someone the community trusts and is familiar with, like Interviewee 3, present the information first. This gives time for the community to process their thoughts on the new concept and think of questions. A second session can follow with the subject matter experts presenting through an interpreter. Attendees will then feel better prepared with questions and much more willing to engage with the outreach through this system.

Specifically, Interviewee 3 suggested outreach to the Grupo de Apoyo para Latinos con Autismo (GALA), About Special Kids (ASK), and Down Syndrome Indiana (DSI). Interviewee 3 was very interested in the project and added to the Stakeholder Group to continue providing input as the State Plan was finalized.

While the Spanish-speaking community is less familiar with options to support individuals with disabilities, the new concepts can be explained through education and outreach. Like the Burmese community, education should include information about the concepts and when they would be used. Outreach is likely to be most effective when presented through a trusted partner, like Interviewee 3. With these strategies in mind, the SDM State Plan can effectively include the Spanish-speaking community in their future outreach initiatives.

Summary recommendations from conversations focusing on culture and diversity

With 8.4% of Indiana's population identifying as a cultural linguistic minority, it is important for the Indiana State Plan to include outreach strategies to include these populations in future efforts to expand the awareness and use of SDM and LRAs. Based on conversations with representatives of the two most prevalent cultural linguistic minorities in Indiana, Burmese and Spanish, the following recommendations are made for future outreach.

Recommendations:

- Outreach topics should be education-based, including:
 - Introduction of basic concepts
 - What is guardianship?
 - What is supported decision-making (SDM)?
 - What are less restrictive alternatives (LRAs)?
 - When supports would be used and why.
 - Importance and benefits of advance planning
- Written outreach should include a note regarding how individual can expect to communicate in their preferred language (interpreters, bilingual staff, etc.).
- Written outreach be image driven and used to generate engagement in a larger conversation. Human connection is most effective.
- In-person outreach should be conducted through a trusted partner.
- Written translations should undergo a two-phase quality control process.

By following the above recommendations, outreach to the Burmese and Spanish communities is most likely to be effective in including those individuals in the broader SDM movement.